

The Continuous Cutaneous Pouch (CCP) or Indiana Pouch

Some practical questions & answers with Karen, a bladder cancer survivor living with a CCP.

A CCP or Indiana Pouch is an internal system of urinary storage which a surgeon creates using the small and large intestines after surgical removal of the bladder. This pouch, (or reservoir) which is connected to the skin by a small stoma, is drained periodically by inserting a thin tube or catheter into the stoma. After the pouch is emptied the catheter is removed. No external bag is needed.

How often do you void with a CCP?

Karen: Time to void depends on the amount of fluids you take in. Early on, it was recommended I void every 2 hours. After complete healing and recovery, most of us void around 3.5 to 4 hour intervals. Once the healing and sizing of the bladder is accomplished, you will learn how to make sure you are empty. It is necessary to move the catheter around and it helps to press on the tummy to assist the fluid to move to other areas so the catheter can 'find' it.

How much does the system hold?

Karen: I think most voids are around 250-300 cc's of urine. It is best to keep the volume lower to avoid distending the bladder. Since there are no muscles to spasm and help to empty, an overstretched pouch will become difficult to empty simply because pockets of urine will be hard to reach with the catheter. Incomplete emptying will increase the chance of infection and the possibility of bladder stones developing.

How do you sleep?

Karen: I void around 11:30pm and again around 6:30am. This all depends on the fluid intake late in the evening. I sleep mostly on my side. Early on, after surgery and while training/getting the bladder into its routine, I did get up after 4 hours. When you get fully trained, you will know when the 'full, tight' feeling signals you to empty.

What about leakage?

Karen: Some of us have leaking problems. Early on, I had some leakage, but now I will leak only if my pouch is full. I wear a small (panty liner type) pad over the stoma on my tummy for insurance. The adhesive backing on that adheres to my underpants – a simple solution that provides security. Surgeons have different methods of devising the stoma. The check valve portion from the small intestine (where it joins the large intestine) is often used in fabricating the stoma for the pouch. Ask your surgeon how he normally does the stoma and how he insures the valve is adequate to protect against leakage.

After the operation, did you use the system right away or was there some other way of voiding until it was healed?

Karen: I had a temporary supra tube to drain while my new stoma was healing.

Since you void with a catheter, what daily maintenance do you need to do?

Karen: I lube the catheter with KY jelly each time. The stoma is tender and needs the lubrication to make the catheter slide in easily. There is no pain or feeling to speak of during insertion. The intestinal tissue doesn't have any tactile sensation so catheterizing is simple and easy. I now use each catheter only one time but for the first 4 years, I reused them by washing with soap and air drying. Medicare is paying for 120 catheters a month now. I irrigate the pouch daily with 200 cc of 0.9% saline solution. The colon derived pouch naturally produces mucus. Irrigation helps to flush out any residual mucus each day. Good hygiene practices apply to all of us, no matter what diversion we have.

Infection?

Karen: There is risk of infection with all diversions. Most of us, regardless of diversion, have them from time to time. I have had probably three UTI's in the five years since my surgery. Symptoms are the same for all of us. Since we don't experience the urgency or pain we would have with an original bladder, we must watch for cloudy urine, stronger smell, chills and fever.

Does the pouch allow you to be more or less normal?

Karen: I think, after adjustment to our new 'normal', we consider ourselves whole with all the diversions. As for body image, there is no change visible unless you are nude. My stoma opening is just lower and to the right of my navel, is about the size of a pencil eraser and sits flush with the body. Some people have their stoma opening in the navel. I would caution anyone [no matter what diversion they receive] to be aware of possible hernias. Abdominal muscles are often inadequate to maintain the stress placed on them by the surgical changes. I would discuss this with my surgeon also. For overweight people, it might be good to put in place a mesh to strengthen the area when the surgery is done. It might help to prevent hernias from developing.

Can I swim?

Karen: Yes. I place a clear, Sure Site cover over my stoma when I swim. They are waterproof and available at medical supplies. I always make sure no bacteria can enter the stoma.

How satisfied are you with it?

Karen: Definitely satisfied!

For more information on bladder cancer visit <u>www.bcan.org</u> Telephone 301-215-9099 or 888-901-2226 info@bcan.org